



November 25, 2013

Comments of Access Living on 1115 Waiver Concept Paper

As one of Illinois' twenty-three Centers for Independent Living, Access Living offers its comments from a standpoint of having been run by and for people with disabilities for more than thirty years. Our goal has always been to ensure that people with disabilities are able to live fully integrated lives in the community. We know that community integration empowers people and saves money, but it must involve a holistic approach coordinated by staff who "speak the language" of independent living, consumer control, person-centered planning and self-determination in all areas of life. The 1115 waiver proposal must be driven by what people with disabilities say they need and by those community programs that have been proven to demonstrate inclusion and consumer control. Illinois must be assertive in its 1115 proposal about rebalancing, that it is about using a greater proportion of Medicaid HCBS dollars on community supports and not institutional care. 1115 outcomes must reflect these core principles.

***Pathway #1: Home- and community-based infrastructure, coordination, and choice:***

**Social determinants of health (page 5):** One tool to attain the laudable goal of tackling social determinants of health specifically in the context of health care is use of the ACE (Adverse Childhood Experiences) biopsychosocial criteria of stress-related indicators. Research with over 17,000 Kaiser Permanente members revealed not only that traumatic childhood experiences were reliable indicators and predictors of stress-related health risk factors but that inclusion of ten basic questions in a patient assessment procedure, with accompanying provider-patient discussion of those factors, resulted in a 35% reduction in doctor office visits, an 11% reduction in emergency room visits, and a 3% reduction in hospitaliza-

tions.<sup>1</sup> The CDC, <http://www.cdc.gov/ace/about.htm>, notes that the study is attracting international attention and its questionnaire being used in several other countries. We recommend use in 1115 waiver services of the assessment procedure and follow through with the accompanying provider-patient discussion.

***Pathway #1A: Home- and community-based infrastructure, coordination, and choice:***

The Home Services Program has a very successful consumer-directed waiver program. We emphasize that this program should not be detrimentally affected by its inclusion in an 1115 waiver.

**The universal assessment tool** (p. 6): Since waivers should be based on identified disability rather than on identified service needs, the uniform assessment tool being developed should:

- Have no institutional bias and link people to services consistent with *Olmstead*'s mandate of the most integrated and least restrictive environment.
- Take into account quality of life as well as quality of care and promote plans of care optimizing rich integration, participation, and experience in the community.
- Elicit and respect consumer goals, including the chosen level of independence, risk, and control of services including personal assistants.
- Contain triggers for deeper probes of functional capacity to assure optimal provision of needed services, and a reassessment of environmental factors should be done after transition from an institution to the community.
- Include in its development and implementation robust stakeholder input, including an active consumer voice in planning, implementation, and oversight.

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<sup>1</sup> "Origins and Essence of the [ACE] Study," ACE Reporter, Vol. 1, No. 1 (April 2003), [http://www.cestudy.org/yahoo\\_site\\_admin/assets/docs/ARVIN1.127150541.pdf](http://www.cestudy.org/yahoo_site_admin/assets/docs/ARVIN1.127150541.pdf); Felitti, V.J., Anda, Robert F., Nordenberg, Dale, Williams, D.F., Spitz, A.M., Edwards, V., Koss, M.P., Marks, J.S., "Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults: The Adverse Childhood Experiences (ACE) Study," Am J Prev Med 1998;14(4) (1998), [http://www.cestudy.org/yahoo\\_site\\_admin/assets/docs/RelationshipofACEs.127152545.pdf](http://www.cestudy.org/yahoo_site_admin/assets/docs/RelationshipofACEs.127152545.pdf); Felitti, V.J., Anda, R.F., "The Relationship of Adverse Childhood Experiences to Adult Medical Disease, Psychiatric Disorders, and Sexual Behavior: Implications for Healthcare," book chapter for F. Lanius & E. Vermetten, eds., "The Hidden Epidemic: The Impact of Early Life Trauma on Health and Disease" (Cambridge University Press (2009), [http://www.cestudy.org/yahoo\\_site\\_admin/assets/docs/LaniusVermetten\\_FINAL\\_8-26-09.12892303.pdf](http://www.cestudy.org/yahoo_site_admin/assets/docs/LaniusVermetten_FINAL_8-26-09.12892303.pdf)

- Reject budget neutrality as a ground to justify service cuts.
- Lead to efficient and timely provision of services without undue delay.

**Goals of a consolidated waiver structure:** Access Living is concerned that the stated goals of the consolidated waiver structure (pages 6-7) omit some critically significant objectives.

- Consumer-directed supportive care. A 2006 study of adults with developmental disabilities in a consumer-directed support program found lower out-of-pocket disability expenses, greater access to health care, more engagement in social activity, greater leisure satisfaction, and better mental health and care for people with low incomes. <http://www.aaddjournals.org/doi/abs/10.1352/0047-6765%282006%2944%5B405%3ACSEHAS%5D2.0.CO%3B2>
- Person-centered service planning. Active patient involvement in treatment decisions and provider respect for those decisions improves health outcomes and quality of life, and is critical in addressing disparities in health care and outcomes. <http://content.healthaffairs.org/content/29/8/1489.short>
- Recognition of the “dignity of risk” in independent community living. The Disability Practice Institute emphasizes that *all* adults have the right to make decisions about their health and care and envisions the clinical role as assisting in implementation of individualized care plans rather than “approval” of choices based on speculation about endangered health or longevity. <http://www.disabilitypracticeinstitute.com/services/%E2%80%9Cdignity-of-risk%E2%80%9D/>

***Pathway #1B: Behavioral Health Expansion and Integration:***

- The State should not invest additional resources in segregated settings like “step-down and transitional living programs,” when research indicates that virtually all people with serious mental illness have better outcomes when they live integrated, independent lives in their own homes and communities with appropriate supports. Step-down and transitional programs are part of an outdated “continuum of care” approach thought appropriate twenty-five years ago. If the right set of supports are provided in the home, there is no need to “transition” through a “continuum” of more

restrictive models. It is actually detrimental to individuals to have to move from one place to the next and “prove” themselves in each setting before they can move on to the next setting.

- Eligibility for home- and community-based services should be decoupled from the standard for institutional care. The State should continue to explore the Community First Choice Option.
- Seamless care transitions (page 7) need to include (1) youth who “age out” of pediatric service provision and (2) hospitals as well as nursing homes and other institutional settings. Service and housing capacity must be expanded to accommodate such transitions into the community.

***Pathway #1C: Stable Living Through Supportive Housing AND EMPLOYMENT:*** Supportive housing is a critical strategy to address instability and inadequacy in housing, which limit the employability and productivity of many citizens, adversely affect family health and stress levels, and impede children's ability to learn. Likewise, supported employment is an evidence-based practice endorsed by the U.S. Department of labor as an effective strategy to help people with disabilities succeed in independent community living. [http://www.dol.gov/odep/pdf/NTAR\\_IB8.pdf](http://www.dol.gov/odep/pdf/NTAR_IB8.pdf) We recommend that the State collaborate with the Illinois Employment and Economic Opportunity for Persons with Disabilities Task Force in developing job opportunities in competitive, integrated, and community-based work environments consistent with the Employment First philosophy. See <http://www.dol.gov/odep/topics/EmploymentFirst.htm>

***Pathway #2: Delivery Service Transformation***

***Pathway #2C: Nursing Facility Transformation*** (pages 10-11):

The Balancing Incentive Program commits the State to increasing access to LTSS and transforming long-term care by incentivizing the provision of HCBS. That Program should meet the vast majority of needs in the community.

Access Living has serious reservations that nursing facilities can and will “drive transformation,” and they are ill-equipped to assume responsibility for the full continuum of care services (page 11). Illinois needs badly to *reduce* its institutional footprint. While we agree with implementing such tools as

bed buybacks to reduce the State's reliance on institutional care, we reject any notion that the State should invest its scarce resources to rebrand, repurpose, and preserve an outdated model of care delivery.

**Pathway #3: Population Health Management** (page 12): We applaud innovative expansion of the health care workforce but caution against overmedicalizing the role of community health workers (page 12) at the expense of consumer control and management of services.

**Pathway #3A: Wellness Strategies:** Wellness strategies should avoid punitive rather than positive consequences (e.g., fees for “inappropriate” use of emergency room services), which serve to incentivize low-income people to stay home and become sicker.

**Pathway #4: Workforce:** All healthcare workers should be authorized to practice to the full scope of their training and competence, and peer services, such as Certified Recovery Specialists and peer navigators, and inclusion of CILs as service providers in deinstitutionalization and housing should be expanded.

**Managed Care Savings** (page 14): The Integrated Care Project illustrates the critical need for adequate provider networkers and rejection of “exclusive provider” models. Illinois should also adopt the lessons learned by California in the rollout of its 1115 waiver including clear explanations to beneficiaries of options and rights in managed care as well as strong monitoring and oversight of managed care plans.

<http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/B/PDF%20BridgeToReform1115Waiver.pdf>

The newly-created Medicaid Managed Care Oversight Task Force should be made an integral part of the 1115 waiver structure.

**Title:** The title “Path to Transformation” could cause undue confusion, given the CHA’s simultaneous use of “Plan for Transformation” for its public housing rebuilding and renovation project. We recommend a clearer and less ambiguous name.

Very truly yours,



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